



Lifelines

October 2014



Transplant Recipients International Organization, Inc.

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TRIO Board Approves Phase 1 Of Post-Transplant Cancer Project

At its fall meeting held October 6, the TRIO Board heard a detailed presentation calling for TRIO to make an initial investment in support of The previously board approved concept for a Post-Transplant Cancer (PTC) project.

The presented overall goals of the project were:

- To use TRIO resources to identify and advance 'best practices' to help patients recognize and deal with post-transplant cancers
- To make a difference in the transplant community by saving lives through prevention, early diagnosis and effective treatment of cancers

An outline of a potentially five-year, large-scale research effort was described, comparing the initial four identified initiatives with an existing mature project by another organization to try and get some practical fact-based ideas of the size and expense of this undertaking. Once this is launched, it is anticipated it will be able to draw significant grant and sponsorships, given the magnitude and impact of the project.

(continued on page 12)

UNOS CEO Brian Shepard Explains Organ Donation on TEDx

The very popular "TED talks" are a new vehicle to educate the public about the need for and the process behind organ donation. In an on-going effort to broaden the communication channels for our important messaging, Brian Shepard, CEO of UNOS, has recorded a video about "Making Life and Death Decisions." The video is now available for general viewing. Brian offers a very different and creative talk that is well worth the 13 minutes to watch it. You can help by sharing this link with others in your network and adding it to chapter newsletters.

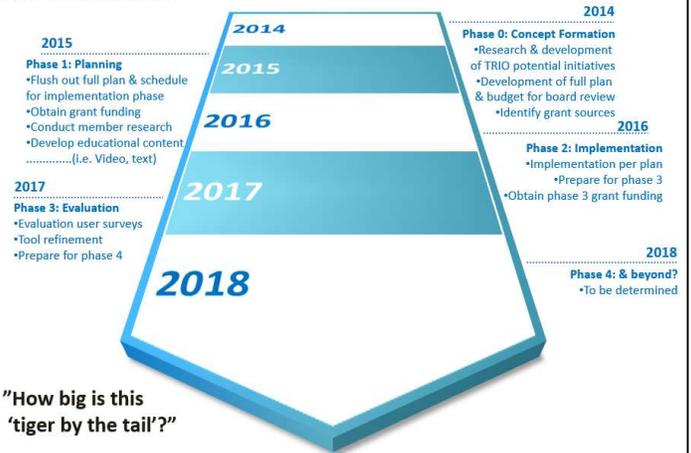
Send your comments to Brian at: brian.shepard@unos.org and mention that you are with TRIO and saw this article in our *Lifelines* newsletter.



To access the video talk, you can click on <https://www.youtube.com/watch?v=kuPGmv2kYZ8#t=39> or click on the image above to link and enjoy his gentle and engaging talk.

TRIO Cancer Project Plan – How long a timeline?

5 Years ??? – see note below...



President's Message



“When it comes to life, the critical thing is whether you take things for granted or take them with gratitude.”

-G.K. Chesterton

Personally, I take my daily life with gratitude. And you, how do you face the things of life?

And as you read this, I am grateful for you and wishing that you too can live your post-transplant life fulfilled and active for more than twenty years, as I celebrate this October 19th, my own 20th anniversary of this heart gift.

Here is how I looked on coming home in 1994, just eight days after that painless surgical experience:



So, why do we choose to take on the challenges of post-transplant life with all those meds and follow-up visits and concerns that come with aging, etc.? By now you do realize it's not to avoid death, right? We are all still going to die someday (although I do believe in living today like I'm immortal - smile). I would suggest that it's because we believe we can live a life of joy, with family and friends to share. As most, I find joy in giving, in paying back through service in many ways, TRIO being a main one, even in offering these thoughts to you, hoping to inspire and lift your day despite those daily life challenges (never 'problems' only 'challenges' to be overcome, a very different mindset in using those two words). I hope you have found your own way to give back, to have fulfillment and joy in life, through TRIO and/or so many other opportunities to make life worth living. Now, twenty years later, despite aging pained knees and those cancer issues mentioned last issue, each day brings such

satisfaction, being busier now in retirement than even when I was working full time, a testimony given by so many in their retirement when life is busy in service and active living. Whether of that age or younger, find your passion and live today to the fullest, never taking things for granted, rather with gratitude and a smile.

Speaking of taking action in service, with the national board's approval, we are moving into the next phase of our huge post-transplant cancer (PTC) project which is now seen as possibly spanning five or more years aimed at saving so many lives through education, best practices for preventing, early diagnosis, and effective treatment of this potentially killing disease. Yes, as a transplant recipient, you and I are at higher risk for cancer over time and with advancing age. But, with education and pro-active steps, we can stay ahead of that (in some cases) 65 times the cancer risk vs. the non-transplant individual. See the article in this issue and stay tuned to see how you can help both yourself and others in your transplant network with the resources TRIO is planning to put at your disposal. But in the end, only YOU can take the needed action, and that is the real challenge, how to change the habits we live with every day to reduce that risk.

Finally, let me celebrate the fact that with the austerity measures your national board put in place earlier this year to address a critical financial challenge, we are well on the way to recovery. Since January 1st, we have increased our operating funds through expense reductions and aggressive advertising and grant revenue by 80%, reversing the negative trending of the past two years of dwindling grants with that diversification. Another contributing factor has been chapter event success with that 10 % donation to support national and, of course, your dues, with \$10 of your local chapter dues coming to national. We all say: ***“Thank you for your support!”***

And remember, there are so many exciting things going on every week, be sure to check out our very active TRIOweb.org web site to stay informed and inspire that daily ***attitude of gratitude*** personal choice for which we all aspire.

As for me, ***“Wow!, above ground another day. This is going to be a GOOD one (again)...”***

*--Sincerely, Jim Gleason, TRIO President
(celebrating my 20th year post heart transplant)*

Free Money to Help with Transplant Meds? Do You Know About the Patient Access Network (PAN)?



... if you already have insurance, even Medicare, and are a patient with a solid organ transplant that meets the financial needs criteria of being within 400% of the federal poverty income guidelines, you can instantly qualify for a grant of \$4,500 to cover the co-pay expenses of your immunosuppressive medications over a 12-month period. For example, the family of two income qualifying amount turns out to be a very generous \$62,920.

An Easy Application Process

... Easily applied for by phone (866-316-7263) or online at www.panfoundation.org and, with an almost instant approval for the fixed full amount of a \$4,500 grant, application is simple and straight forward with no proof of income required (although always subject to future audit, if requested). The 12-month period starts at the time of the approval and is subject to annual renewal at the end of 12 calendar months, not over the calendar year.

Beyond that income limit, the only other requirements are a qualifying medical condition and having current insurance coverage. Once a receipt is submitted for brand name immunosuppressant drug prescription or refills, the co-pay you paid is applied against the grant, and you receive a check at the end of the month for that amount.

Simple and so helpful. Spread the word to your network and chapter members.

Are You Reading This?

Obviously YOU are, so this message isn't directly getting out to the intended audience of those who are not opening the e-mail, or not reading the overall message in that e-mail or not linking to this electronic issue of the October Lifelines, or once there, not reading it. But **YOU are** doing all those steps - YOU are one of a special minority (see final note below...) and we thank you. You are the audience we reach and thus ask this question: "Why?"

Why are we asking?

Our communications committee is working on improving the effectiveness of our communications. Understanding why you are a reader can provide insights that will help expand readership so important TRIO information and education gets to all

TRIO members. Only **IF** those members get the information can they become aware and able to support with their action important campaigns such as the earlier protected class HRSA issue or upcoming TRIO post-transplant cancer initiatives.



TRIO National Readership Survey

You can help with your action . . .

Share your answer to the question: "**Why did you read our October Lifelines and this article in particular?**" Click on the image or [here for a one item survey](#) (the shortest you've ever taken). If reading this in hard copy, go on-line to:

<http://survey.constantcontact.com/survey/a07e9gtyzs8hwnlftoz/start>. Alternatively, send your response to info@trioweb.org or you can contact TRIO president, Jim Gleason, at GleasonJim@aol.com or (609) 877-4493 to share your insights as to why you read this, and if you have any thoughts about why others do not.

Did you know?

Industry reports less than 10% respond to surveys, and only about 33% even open e-mail messaging. While TRIO is seeing better results (thanks to YOU), this is far from our goal of reaching 100% of membership with our communications. Special Note: if you are one of the six who already responded to this survey in the Summer issue, "**Thank you!**" - there is no need to respond again. Instead, please pass along this issue and encourage fellow TRIO members to respond now.

Thanks for reading and helping with this **big "C"** concern: **Communications Effectiveness.**

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TRIO's Public Policy Initiatives

The TRIO Public Policy Committee, along with other national organizations, is actively involved in a number of transplant issues. On September 16, the Committee participated in the liver allocation forum held by UNOS. The discussion focused on a recent proposal to reduce the number of UNOS areas for purposes of liver allocation. The participants at the day-long conference raised many issues concerning the mechanics of the allocation process, required resources, funding, and fairness. Based on the many comments at the forum, UNOS now plans to further study the liver allocation issue and has delayed any recommendations until such studies are completed.

The Public Policy Committee has also reviewed newly introduced Congressional legislation entitled "The Living Donor Protection Act" (HR 5263) sponsored by Representatives Jerold Nadler (D-NY) and Michael Burgess (R-TX). The principal focus of the bill is to prevent insurance discrimination against living donors. While no action on the bill is likely during the current session of Congress, re-introduction of the legislation is anticipated during the next session. To express your support for the bill you can download a sample letter ([click here](#)). You can find your Representative's address by following the links available in the sample letter of support.

TRIO, in conjunction with Medicare Rights Center, has signed on to a letter sent to the Centers for Medicare & Medicaid Services (CMS). This letter seeks clarification of rules explained in a Frequently Asked Questions (FAQ) published by CMS around the interplay between eligibility for ACA Marketplace coverage and Medicare eligibility for people with disabilities, ESRD, and seniors. For the transplant community, the clarifications seek to ensure that ESRD beneficiaries can get the coverage that works best for them at the least cost. You can find that FAQ at <http://www.cms.gov/Medicare/Eligibility-and-Enrollment/Medicare-and-the-Marketplace/Overview1.html>.

TRIO also signed on to a letter to the Health Resources Administration (HRSA), which funds the organ transplantation networks, to seek information about the federal role in living donation. The newly-formed Waitlist Zero is an organization established by Josh Morrison who is a living donor and the co-chair of the TRIO Youth Circle. This letter is aimed at reviewing current

HRSA support for living donation and encouraging federal support for increasing knowledge about the process for and benefits of living donation.

TRIO meets regularly with many other coalitions to promote the transplant process. TRIO participates with the Transplant Roundtable, a forum where organizations representing patients, professionals, and institutions can promote funding for transplant and protect the transplant community's interests in federal legislation and regulation. TRIO also participates in the Coalition for Part D Access to continue to protect access to drugs for transplant patients and with the Chicago Transplant Ethics Consortium on living donation. TRIO also continues its involvement with many UNOS subcommittees.

The Public Policy Committee needs your help and involvement. Each TRIO chapter should consider identifying a member or members who have an interest in public policy. Those individuals can help review national issues and monitor state and local activities that affect the transplant community. TRIO needs and wants input from all Chapters to assist in formulating any national position our organization might take. Each Chapter is also more familiar with and better positioned to understand the impact of legislation at the individual state level. As these members are identified, we will establish a national mechanism to obtain and share your valued input on state level initiatives and on any national positions TRIO may wish to consider. Contact Rodger Goodacre at rodger.goodacre@gmail.com or Ted Lawson at tedlawson320@aol.com for more background and to become part of the Public Policy Committee.

--Rodger Goodacre, Member, TRIO Board of Directors;
Chair, Public Policy Committee

Follow-up information and Congressional Briefing Report on the Partnership for Plan D Coalition

TRIO's participation in the Partnership for Plan D Coalition helped to successfully reverse the attack by HRSA on six protected classes of drugs. Continued vigilance is needed to insure that doesn't come around in a different way in the future. To review the Congressional Briefing event report, go to:

<http://www.trioweb.org/images/files/resources/downloads/PartnershipforPartDAccess-CongressionalBriefingSummary.pdf>

Liver Allocation Under Study; What Is TRIO's Role?

We've learned from history

About twenty or more years ago, a change in the liver allocation rules tore TRIO apart. These many years later we are still working hard to recover those lost chapters and members who left after the TRIO board came out in public support of one side of that issue that was different than what they felt. The organ donation and allocation process is a very complex one, often with controversial debate over any change in the rules. The new kidney allocation policy that goes into effect December 4th, a result of over ten years of study and discussion, is a recent such topic. The lung allocation story of just a couple of years ago in Philadelphia is yet another example of passionate response coming from both sides of the issue: a child receiving priority over waiting adults, given the medical challenges that supported the allocation rules then in place.

Now we have a similarly controversial effort to address the disparity of waiting times across the country and the MELD score levels at which patients get transplanted in different regions.

In changing policy, UNOS follows a strict process of very deliberate study that engages all affected parties, especially patients and the public in general. Nothing happens without going out for public comment that allows each and every individual and organization to weigh in on the issue from their points of view. When an organization such as TRIO speaks out, it is representing its membership as one voice, carrying with it the weight of membership numbers. The challenge is in how to gain the consensus of a membership that holds diverse opinions on these issues. Even with a difficult process that is done effectively, many members feel left out and leave an organization, a price any group has to pay in such cases.

TRIO's role on issues of controversy

TRIO has taken the path of encouraging individuals to become educated on an issue and then tries to make it easy for them to speak out where their voice counts. We gather and provide resources that address an issue from both sides of controversy, encouraging chapters to host discussions with local experts to insure the facts are available as members form their own position. TRIO provides the pathways to that Public Comment opportunity that goes to the UNOS committee members who are involved in

study of the issue and are tasked with developing policy that most fairly allocates the scarce donated organ gifts. Sadly, even when the issue is publicly debated and that pathway offered for one's voice to be heard, too few take the time and effort to provide that input.

On the hotly debated kidney issue, there were fewer than 300 comments submitted. A widely advertised recent UNOS-sponsored town hall liver forum was held in Chicago and available on-line. Many presentations offered strong evidence both for and against the concepts currently under study of creating liver regions different than the current generalized ones, drew about 500 attendees, 300 of which were able to participate from their home and office computers. Some had already reacted strongly, looking to create a campaign in protest of the proposal, but there was no such proposal yet. This was still just open discussion towards creating a proposal from several ideas.

Offered support and guidance, members can play a more effective role in addressing these issues. Hundreds of individual responses to the key players in an issue can be significant, and each of us has the potential to be heard in that way, sometimes even stopping a government proposal in its tracks (see below)

TRIO will lead

TRIO will continue that policy of helping our members to learn and understand the issues, encouraging effective individual actions directed where it can have real impact. Our members will continue to serve on UNOS committees, providing patient perspective to issues under development.

TRIO surveys to gain consensus in the past have failed to gain any significant response and we are not going to take a position on controversial issues without having the support of the full membership so as to avoid potentially lethal damage to the organization as was the case back in the early 90's.

You are the voter. Get educated and make your voice heard as you see fit. Trust that where we do have an issue that is clearly supportable by our membership, as was the case earlier this year on the HRSA Part D drug classification case, TRIO will speak out and join with other groups to protect patients' rights, organizing our membership to join in such fights.

The Communications Challenge



TRIO, as is the case with every other large organization today, is faced with the challenge of communicating with its membership. As an example, in an annual appeal for donations, one

organization sent out 16,000 beautiful snail mail appeal brochures at a cost of over \$8,000 just for the printing and postage with an amazing personal story to support the need. Would you care to guess the actual return – go ahead, you’ve seen such mailings in your own home – how much? Their actual result: 60 donations that barely covered the expense noted above. And that doesn’t include the internal design and administrative manpower expense behind the campaign. In fact, they do it not for the money, obviously, but just to keep the organization in front of the audience (and it adds to the appeal for their other grant solicitations).

In our case, we are not asking for donations, rather we are sharing information, both news and educational items of interest. Our earlier traditional communications were very costly and slow, plus we had no idea of how effective they were in terms of members actually reading them. Along with most groups today, we have moved to electronic media – the web, monthly e-news, quarterly electronic Lifelines, Facebook, etc. – at SIGNIFICANT savings to the organization /membership. This allows for colorful active documents that link to expanded and enriched materials.

A big benefit of this new format is we can track the membership engagement with that messaging. Using that word carefully, ‘engagement’ means we can see who opens and links to the material, but still actual readership is only known to the individual, unless they respond to an embedded survey, for example. That’s both the good news and bad news. Good in the sense of not wasting money with an audience that doesn’t read the mailings, and good in the sense that we now know more about that engagement. The bad news is that we now know that engagement. While we see better results than the industry average for our type of company (TRIO’s

OPEN rate is 47% vs. non-profit industry average of 22.7%) that still means 53% of our mailing is not getting to the intended audience. The CLICK-THRU stats are much less, so when Lifelines is tracked by that E-News item link to the issue, we see that only 13% download Lifelines.

Speaking with other national groups, they report even less and tell us we are doing good. But, I’m sorry, we can’t accept that over half of our membership isn’t seeing those important messages. We somehow have to do better. Keep in mind, we don’t have e-mail addresses for all members and many may be receiving them through their chapter’s forwarding them through their own distribution process, and that doesn’t count any who may go to the web site for that material. The real answer is that there is no one answer that reaches all. An effective organization must use multiple channels to accommodate the styles of membership contact. That is what TRIO is working on today, addressing the communications challenge in creative new ways, along with YOUR help in passing our messages out to your network. Thanks for being a part of that TRIO effort.

- Jim Gleason, President
TRIO Board of Directors

Do YOU have a story to share?

Lifelines welcomes your article contributions for consideration by the editorial board. Suggestions for an article, either one you write or a topic you would like to see authored by someone else, should be submitted to info@trioweb.org in summary form.

The editors will respond and, if accepted, you would then write the full article for use in an upcoming issue.

Become a part of the action!
Offer your ideas today!

UNOS New Kidney Allocation DVD

Our latest addition to the Transplant Presentation Library, titled **“The Right Kidney for the Right Patient”**, was recently recorded at a TRIO sponsored educational event.

We will get this timely program out as soon as possible (out of sequence) to the chapters for use in offering education about the December 4 ‘going live’ implementation for this long anticipated change in how kidneys will be allocated. We hope to have this DVD in the hands of chapters by the end of October.

TRIO Is Taking On Post-transplant Cancer

With approval by the Board, as reported on Page 1, TRIO will move forward to research possible ways to support the transplant community in their dealing with the much higher risks for cancer in the years after solid organ transplant. A small investigative team has been interviewing medical professionals and researchers across the country and asking the question, ***“What can TRIO as a national organization do to support them in their work with patients facing cancer after transplant?”*** Over recent months, we have found a very receptive and generous response from physicians and others with their time and sharing of resources on this important topic.

In all honesty, at this stage we don't know how large this undertaking is, possibly a small effort involving gathering and posting of educational resources, or a huge multi-year project involving research and many initiatives. One larger idea involves coming up with ways to change recipient's habits in following 'best practices' for preventing, discovering and treating the various forms of cancer that are different risks by organ type. Posting education is easy, changing people's habits is much more complex. Just think back on the not-so-simple task of communicating to our membership, as discussed in another article in this issue.

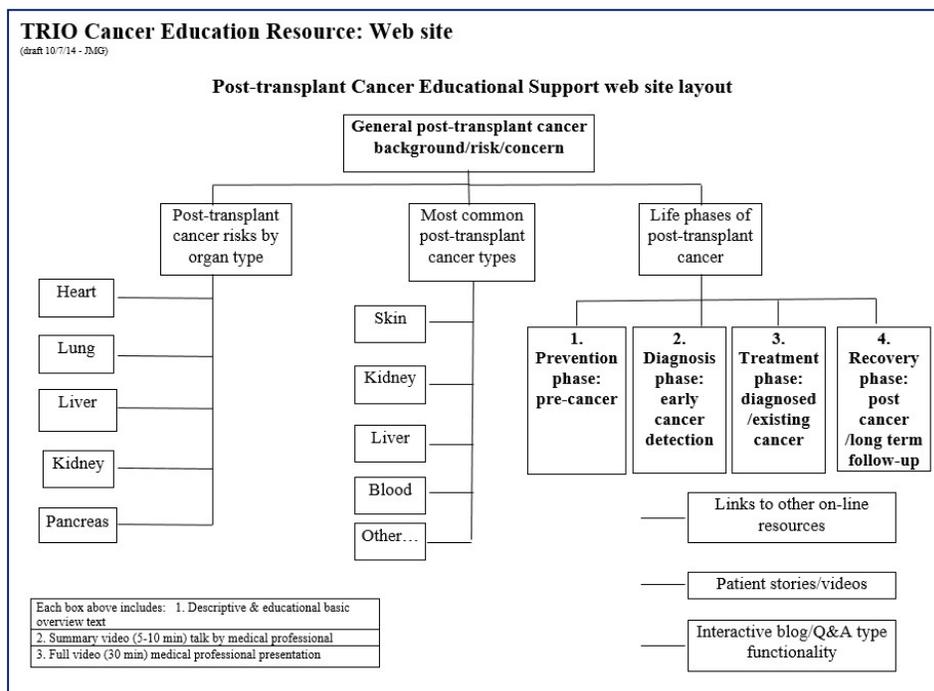
In the months ahead, expect to see and hear much more on this very important issue. Too often cancer is the cause of death in our TRIO membership. That led us to consider taking on this extreme multi-year challenge that may even save YOUR life in the long term.

You can help, as you will see in future communications.

TRIO Maryland Participates in 2014 Transplant Games



(Left to right) Pat and Bill Sneed, from North Carolina, with Marty and Michele Maren, TRIO Maryland Chapter. Bill is caregiver to his wife Pat, who is a double lung recipient.



Team Maryland is a small group of about 35 athletes. Twenty of those are TRIO Maryland Chapter members. Most of the team attended the 2014 Transplant Games of America in Houston, Texas. The games were exciting and fun, but I was unsuccessful in connecting with other TRIO chapters. The hectic schedule didn't offer much opportunity to connect.

The games offer a great chance for TRIO representatives to reach out to 2,000+ game athletes and guests to share what TRIO is all about.

Just thinking out loud: let's not pass up the 2016 Transplant Games in Cleveland as a vehicle to expand and grow TRIO. Let's make plans! Let me know if your chapter is going to attend.

--Marty Maren, Member, TRIO Board of Directors
President, TRIO Maryland Chapter

Chapters Helping Chapters

Over the years, there is a common life cycle that many (but not all) TRIO chapters face. A new group becomes a chartered TRIO chapter and, with the passion and enthusiasm of new leadership attracting new members, engaging members in creative and new ideas, membership grows and a new social network forms. This is a special time, like when a family comes home with a new baby, there is excitement and everyone wants to hold the baby. That excitement is similar to getting involved in chapter gatherings and events, a time of fun that may, in turn, draw in yet more new active members, spouses, and family.

This excitement and growth may continue for several years or more. Sometimes, the same leadership remains, usually strong leadership that one day changes due to illness, a move away from the area or sadly, even death. Initially, nobody feels they can live up to the now legendary level set by that former leader. A chapter can slowly fade under such circumstances, some may even close (if not formally, at least in terms of having no meetings or events to sustain the interest of the membership). Sometimes a dedicated follower will step in to fill the void, usually very tentatively, not feeling they have what it takes to do the job as well as the former leader, but at least somebody is back at the helm, often leading a very downsized chapter of followers. That interim leader sometimes creates the bridge to a future stronger leader or one with a new vision of the opportunity for their chapter and that chapter may experience resurgence, coming back up from the valley of diminished membership and activity . . . and the life cycle continues.

This brings up two best practices that a chapter could adopt to create a sustaining organization that would last through times of life-cycle challenges.

First, look to constantly develop and train future chapter leadership, often by inviting members with the right skills to fill the various officer roles of the chapter, serving in close teamwork (understudy?) with the chapter president. Yes, I know, it's easier to "just do it myself" but that is exactly what traps one into that role for a "lifetime" of service which, in turn, sets the chapter up for that failure situation described above. There is real value to officer rotation, not just in

sharing the load, but also in creating new vision, fresh ideas, and revitalized energy.

Secondly, there is power in developing a mentoring or partnering relationship between chapters. That can be done on several levels. An established chapter has much to offer the newly formed chapter. In our local Philadelphia experience, the two-hour-away Baltimore-based newly formed Maryland chapter was such an opportunity as their members/leaders traveled to sit in on a meeting and learn from the sharing. The Philadelphia chapter was still in long-term recovery mode after a hiatus of several inactive years with a dedicated core of regular members attending monthly meetings, supporting special events and activities. That new Maryland chapter quickly overtook the almost twenty-year-old Philadelphia chapter with a full calendar of activities and membership growth, even recently hosting the national board meeting. There are many opportunities for chapters to support each other, even if they don't have the benefit of being within driving distance. Today's technology of Skype video conferencing or just connecting for conversations by phone make mentoring or partnering possible no matter the distance.

If you see the need in your own organization or can offer support to another, or simply could benefit from just open sharing with another chapter, reach out to TRIO's Chapter Council Chair, Marty Maren, to explore the possibilities based on his being a central point with insight to needs or matching opportunities.

No chapter is alone. That's the benefit of a national organization with shared resources and experiences. It's up to you to reach out and make that combined strength work for the good of all.

—Jim Gleason

*President, TRIO Board of Directors
President, TRIO Philadelphia Chapter*

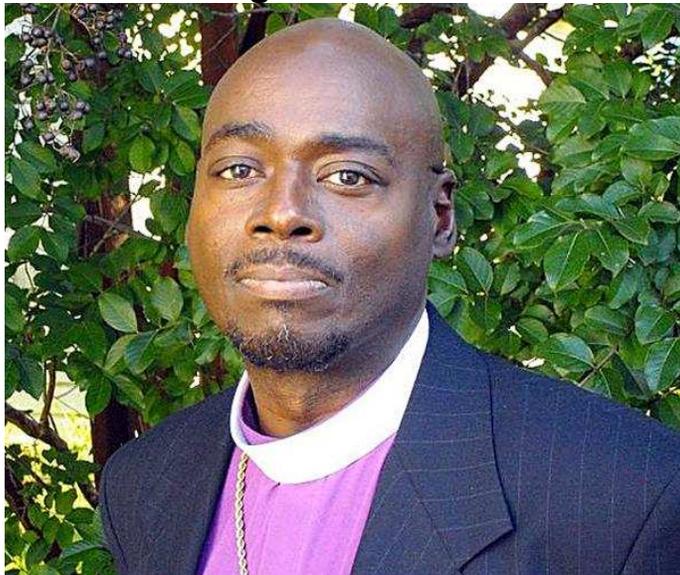


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The Re-making of Me



Statistics, percentages, and averages. Numbers on a board . . . Really? I'm not a number, I'm not the grant total or the aggregate. I am a son, a brother, a father, a preacher, a breathing, walking, talking and not totally unattractive individual.

I matter to those who love me, and I care for all whom I have come to know and appreciate. Yet, it was a stranger, someone I never met. We never went to breakfast, never had dinner, never played basketball or golf, nor a game of spades. Even now, I can't describe his features. I never met the guy, but a part of him lives on in me, and I can live because of his unselfishness and the unselfishness of his survivors.

At some point in time, this man made a conscious decision to be an organ donor. Wow! I had thought about it, but I didn't follow through on it. It was an afterthought. It was something I would do, one day. At the time, I was healthy and vibrant. I could preach for 45 minutes and bore people out of their skulls. I ran around town and completed my errands, played with my kids, went to the beach, and ate crab legs 'til I got sick! Oh, yes, and I would become an organ donor—one day.

Then, out of nowhere, I found myself in the hospital, needing a kidney transplant. I did not have diabetes, I was not overweight, I did not have high blood pressure. I was not even in my 40s! I ingested mold while cleaning and lost both my kidneys. I figured I would be dead in five years or less! Less, because suicide became a very real alternative for this Baptist preacher.

I did not want to die, but I did not want to be on dialysis, either.

Then this guy changed my life! I don't even know his name. I don't know where or how he lived. I'm sure he had a family who loved and cared for him. He was more of a man than I was: he became an organ donor while I thought about it. I don't even know how he died. But his death gave me life.

Today I am an organ recipient *and* a registered organ donor! The re-making of me was to not put off for tomorrow! Today it's not about thinking about it, but being about it, making a difference. Now, I donate my time, my efforts, my all to make sure the man I never met, did not die in vain.

I'm not a number, a statistic, a percentage—I'm a father, a son, a brother; and my family has me still. Because that brave nameless, faceless man had the courage to donate more than his time, efforts and money. He gave the life of life, he gave me a kidney. I hate that he died, but I'm glad that he did not die in vain.

-Rev. Dr. B. Angeloe Burch, Sr.
(written for Donate Life NC)

TRIO DVD Library Grows Into Its Sixth Year of Presentations

The TRIO Presentation Library is growing into its sixth year of publication in 2015. With the support of Astellas Pharma, this has proven to be an enduring concept with 63 titles available to TRIO members. Two new programs will be released soon: "Transplant Life Experience from Two Sides" by George Alburger, MSN, RN and lung recipient and "Returning To A Life's Dream" by Lunne Samson, Esq., retiring CEO of the well-known HelpHOPELive organization. Soon to be recorded is the title "Staying Healthy Years After Transplant: Change in Focus of Care Over Time."

In the months ahead, expect to see an outgrowth of our post-transplant cancer initiative with presentations by noted physicians who treat the various forms of cancer for which transplant recipients are known to be at higher risk.

See the full catalog listing on the TRIO website under "[Resources](#)". And, remember, the invitation is always open to present recorded presentations for review and inclusion in this library, so others can benefit from your local resources.

The Kidney Paired Donation (KPD) Conundrum

Imagine you are fortunate enough to have a living kidney donor. Your donor is healthy enough to donate but you learn they either have an incompatible blood type or you carry an antibody that will reject this person's kidney. Having these antibodies is commonly referred to as being sensitized and this will make it more difficult to find a compatible donor. These antibodies develop if you've had a blood transfusion, a previous transplant, or for some women who have given birth. Approximately one third of all potential living donors are not compatible with the person they intend to donate to.

While this can feel devastating to learn, better anti-rejection drugs and Kidney Paired Donations (KPD) also called paired exchanges, chains or swaps, allow these incompatible donors to help their intended recipient by donating to another recipient who has an incompatible donor. In short, these two recipients swap their incompatible donors. KPD's have the potential of adding thousands of kidney transplants a year if a centralized national program is developed that will register all incompatible pairs.

The likelihood of finding a compatible pair is increased when there are many incompatible pairs within your pool. However, there are exceptions to this when a pool contains many difficult pairs to match.

Here's the Conundrum. Let's say you and your incompatible donor want to pursue a KPD. The following are the different types of KPD programs developed.

1. A transplant hospital has a dedicated KPD program with only their patients.
2. Some hospitals share their incompatible pair lists with other hospitals within their immediate area.
3. Hospitals like the Mayo Clinic have facilities in different markets and they share their information with the other hospitals.
4. Some hospitals are developing relationships with other transplant hospitals in different parts of the U.S.
5. There are three national organizations that don't do transplants but they have developed a "cooperative" type of relationship with many hospitals.

There isn't one national "list" like the kidney transplant waiting list for a deceased donor kid-

ney. Here are your potential options to maximize your opportunities for a match:

If your original transplant hospital has a KPD program, register with the hospital.

- Look for other transplant hospitals with KPD programs and register with them. Find other KPD programs working with many hospitals as described above in points #2, #3 and #4.
- Register with one or all of the national "co-op" programs as described in point #5.
- Review the Kidney Paired Donation Pilot Program provided through OPTN/UNOS ([click here](#)). While this UNOS program is described as a 'pilot', it is beyond that stage of development, awaiting federal approval to remove the word "pilot" from the program title.

If you are a relatively easy incompatible pair to be matched, (i.e. a recipient with an A blood type and not very sensitized, and you have an O blood type donor), you might not need to be registered with many KPD programs to find a match. If you are a pair that is more difficult to match, i.e., a recipient that is highly sensitized, then you may want to register with as many programs as possible.

KPDs are relatively new to the transplant community and will go through many changes in the next few years. Currently, they may not be structured in the most efficient way, but hopefully in the future these programs will work together to help those who are most in need.

For a more detailed description of KPDs, go to: www.lkdn.org/LKDN_Paired_Exchanges.pdf

Harvey Mysel is a two-time kidney transplant recipient. Harvey is a member of the TRIO Board of Directors and is founder of the Living Kidney Donors Network, a non-profit organization offering FREE workshops, webinars and private consultation to educate people in need of a kidney transplant about living kidney donation and helps prepare them to effectively communicate their



need to family members and friends. The LKDN assists those who are interested in being a living donor through the transplant process. The LKDN website is: www.lkdn.org and Harvey can be reached at: harvey@lkdn.org

A Well-Informed Caregiver Is Essential

A well-informed caregiver with appropriate emotional support is essential to the well-being of the transplant patient.

Like most caregivers to loved ones pre- and post-transplant, we had a lot of questions and longed for support and understanding. We were unable to find a group dedicated to the transplant caregiver and felt our needs were not being met on the many forums dedicated to transplant patients. That is why we founded a Facebook group, Transplant Caregivers – Partners for Life, on September 8, 2013.

Our goal is to provide a safe haven designed exclusively for caregivers of loved ones pre- and post-transplant. Our virtual forum is the platform for discussions on the unique circumstances, challenges and opportunities faced during each phase of the transplant process. Most importantly, we have created a community to help others know that they are not alone on this extraordinary journey called transplant.

We have found that the role of the transplant caregiver is different from other types of caregiving. Pre-transplant, we do not have the opportunity to process our emotions as other caregivers may. We do not go through the natural steps to eventually accept that the end is near. We are stuck in limbo, just waiting. The reality is that we are watching our loved ones slowly deteriorate as life slips away and yet they might be fortunate to be the recipient of a life-saving gift. Post-transplant our situations are unique; we need to learn so much. It's a drastic change from pre-transplant medication and diet changes, learning to understand new symptoms and understanding the psychological and emotional hurdles. We need to shift gears and let our loved ones become more independent. We need to remember that how we treat our loved one has everything to do with their emotional and physical recovery. But most of all, we have to learn to live again! We've been given a second chance, a gift that can only be re-paid by being dedicated to taking care of our donors' gift(s) and bringing awareness to the cause.

To date, our forum consists of over 550 caregivers from all over the world. They are caring for loved ones at different phases of the transplant process and in need of different types

of transplants. We are inspired each day by the heart-felt stories provided by our members. Topics on the facebook page vary from day to day. A typical day may consist of discussions on general emotional support, questions on how to successfully fundraise, what to expect during the transplant evaluation process, etc. We have enough representation that each question or comment is addressed by a member who can provide helpful insight and support. We are grateful that we have a mechanism in place to help others by sharing similar life changing experiences. We are all ordinary people thrown into extraordinary circumstances.

If you are a caregiver of a loved one pre- or post-transplant, please join and share your extraordinary journey, knowing that you are not alone. To join, send an email request to join@transplantcaregivers.com (<https://www.facebook.com/groups/PartnersForLife/>)

-Renee Ambrosio-Alexander, Co-Founder, Caregiver
-LeeAnn Fitzgerald, Co-Founder, Caregiver



Chapter Council Report

The second quarter Chapter Presidents Conference call was held on July 21. It wasn't just that 12 chapters participated, but it was the amount of chapter activity relayed that was encouraging. Each chapter spoke proudly of their activities and projects and got a chance to boast. The conversation provided new chapters with ideas of activities to do and how to get started. Even the newest chapters, Pacific Northwest and Central Texas, had a lot of ideas to share.

Everyone was excited and engaged on the call. This call proves that whether you are in a small chapter or a large chapter, everyone has something to offer to support transplant living and organ donation.

The third quarter teleconference will be held on October 20 at 8 p.m. eastern time. On that call, I plan to focus on a topic and share ideas on how to grow chapter membership.

-Marty Maren, President, TRIO Chapter Council
President, TRIO Maryland Chapter

TRIO Chapters Partner for Patient Education

As chapters often look for community event opportunities in support of their TRIO mission, a popular one is to host a **‘Transplant Candidate Information Workshop’** using local patient and medical professional speakers. Significant challenges associated with that initiative include getting speakers, finances to provide food and materials, a location for the event and how to communicate to the intended audience especially since the HIPPA rules prevent hospital programs from releasing patient contact information.

A chapter ‘best practice’ can be seen in chapters who have found a way around all those challenges by partnering with a local OPO or medical center, offering TRIO support with volunteers, patient speakers, advertising and even offering a TRIO table display inviting candidates to TRIO support meetings. The advantages to this approach are many as evidenced by current events such as the TRIO Maryland’s **The Transplant Journey: An Educational Transplant Conference**, a coalition between host, TRIO Maryland, their OPO, The Living Legacy Foundation, with staff from The Johns Hopkins Comprehensive Transplant Center and the University of Maryland Transplant Center. With over 21 speakers, 15 workshops and 350 registrants, you can imagine the expense and effort behind such an event and how much can be shared with that partnership.

On a smaller scale, TRIO Philadelphia picked up on a candidate information event that their OPO had dropped some years ago due to expense and falling attendance. The list of challenges above kept the initial event offerings from any significant turnout, especially the communications challenge. This year the chapter partnered with a local Crozer-Chester hospital kidney transplant program. That program organized the speakers, provided the meeting venue, offered food service, printed flyers and mailed/advertised the event with TRIO’s support. TRIO will have four members on a panel of recipients and donors to support the presentations by the medical staff as well as hosting a TRIO information table and guiding the expected 100+ guests (many nurses and social workers gaining CEU credits for attending) to the auditorium, a great promo for TRIO awareness.

In another Philadelphia example, the following

week, patients will host the semi-annual transplant speaker event that draws about 80 attendees at the Hospital of the University of Pennsylvania with their transplant program providing speakers, patient invitations, advertising, free parking and a buffet lunch. The organization also does the pre-registrations and, in so doing, collects patient-provided contact information for follow up and future events, a nice solution to that HIPPA patient information privacy challenge.

As an added advantage to these event partnerships, TRIO is often allowed to record the presentations for inclusion in our Transplant Presentation Library of DVD programs, thus extending the educational outreach to TRIO members around the country.

So, if your chapter is looking for a powerful event with limited resources, try this partnering with your OPO or transplant center. Everybody comes out a winner!

Board Approves Phase 1 of Post-Transplant Cancer Project

(continued from Page 1)

To get Phase 1 off the ground, the board approved funding for the design of the first initiative: an ambitious TRIO-sponsored cancer education website. This resource will be focused on transplant recipients and their higher risks of cancer, risks that increase in years after transplant and along with our ageing process with life extended through transplantation. That site will feature medical professional video presentations on all aspects of this issue by types of transplanted organ, types of cancer and phases of cancer life cycle, offering patients “best practices” addressing prevention, diagnosis, treatment, recovery, and long-term survival.

This is not seen as a short-term fix, but rather, a long-term investment of manpower and effort to create a significant set of resources that would build off the foundation of research into a training kit for a PTC workshop that could be carried out by TRIO chapters and other groups with similar interests, such as transplant programs around the country.

Click on the [PTC Project Presentation](#) to link to the full slide show that the board received at this meeting. Stay tuned for upcoming opportunities to support and get involved in this effort.

You can be a part of this life-saving effort!

When Is Too Good, Not Good? (One Person's Story)

As transplant recipients, we monitor our levels of immunosuppressant drugs to ensure that they are at levels to prevent rejection. These drugs suppress our immune response and, in so doing, keep our immune system from attacking and rejecting the transplanted organ(s). As long as the levels do not drop too low they serve their purpose of preventing rejection. But, no one said what might happen if the levels were too high, nor what the signs (symptoms) of elevated levels might be. Well, too high is not good – and it caused my transplanted kidney to almost completely shut down, put me in the hospital for a week and on supplemental dialysis for another two weeks. Initially treated as an organ rejection response with IV administered prednisone, it was neither a rejection response nor an allergic response.

What caused the immunosuppressant drug levels to go sky high [rapamune level of 34.1 and prograf level of 28.3 the morning after my admission] was my body's reaction to the antibiotic clarithromycin that I had been given along with amoxicillin to treat a H. pylori infection in my intestine. This was not an allergic reaction to the antibiotic. My creatinine levels reached 5.7 but dropped to 3.1 after being off of dialysis for 12 days, and continued to improve to 2.6 but not my previous level of 1.7. And there is the second lesson learned as I had checked with my nephrologist to see if the clarithromycin would effect my kidney. The nephrologist said "no," perhaps because this antibiotic acts in the liver. The lesson is that there are so many new drugs and drug interactions that it is also important to check with your transplant doctors as they have the most current knowledge of interactions. Neither my pharmacy or FDA's medwatch site identified any concern.

The antibiotic clarithromycin is metabolized in the liver, but prograf and rapamune, the immunosuppressant drugs that I've been taking are also metabolized in the liver. This antibiotic interfered with the breakdown of prograf and rapamune in the liver so the levels of these immunosuppressant drugs increased to toxic levels. Yes, the same drugs that suppress the immune system and prevent organ rejection may be toxic to the kidney at high levels, actually killing kid-

ney cells. I've recently heard that all "mycins" may cause this reaction.

Now, in retrospect, I've tried to consider possible symptoms. There were no typical allergic reactions such as rash, swelling of the lips, or shortness of breath. On the third and fourth day of treatment with the antibiotic, I wanted to sleep most of the day. Then there was a significant decrease in urine output on the morning of the fifth day before going to the emergency room.

-Charles W. Dane,
2006 Kidney Transplant Recipient
Member, TRIO National Capital Area Chapter

TRIOweb.org: "Did you see . . .?"

On the TRIO web site, <http://TRIOweb.org>, under UNOS News, there is a new invitation for YOU to attend on-line the upcoming UNOS Town Hall meeting Thursday, October 23rd from 2 until 3:15pm (eastern time). The new kidney allocation system (KAS) finally goes into full effect on **December 4, 2014**. As a follow-up to resources that have been provided to the community in preparation for implementation of the new kidney allocation system, this question and answer session with a panel of subject matter experts will be offered to provide a venue for members to ask questions and to facilitate discussion for better understanding.

As one who, along with 200+ others, spent eight hours on-line listening to the recent UNOS Liver Forum as experts presented pro and con studies about the current work being done to level out the wait time for a liver transplant across the country, I can share that it sure beats the time and expense of traveling to such events. [You can see summaries of this forum on the TRIO site](#), a great way to understand the issues and alternatives under consideration in this highly debated topic where new liver specific regions are only one option being discussed. Over 200 others travelled to this event in person, for an audience of almost 500! But you can still catch up on our web site.

Stay tuned into such important issues by regularly visiting the TRIO site, getting educated so you can speak up on donation and transplant topics in your network and community.

Re-Designed OPTN Website Launched September 26



The Organ Procurement and Transplantation Network (OPTN) website (<http://optn.transplant.hrsa.gov>), a primary source of information about organ donation and transplantation in the United States, has been redesigned with a new look, reorganized content and a mobile-friendly design. The new site offers a number of new features to provide visitors with a more user-friendly experience.

The OPTN site receives about 620,000 visits and 2.8 million page views per year. It originally launched in 2001. Key audiences include transplant patients and their families, living donors, transplant professionals and researchers.

New features

- The new mobile-friendly design allows visitors to access and view content easily--whether they use a smart phone, tablet, laptop or desktop computer. Research shows that use of mobile **devices to access web content has grown rapidly.**

- Improved design and usability will help visitors find content more readily and view it in a simple, attractive format.

- Video content has been added for professionals and patients to provide an accessible alternative to read-only materials.

Reorganized navigation and content

Several sections of the site have been updated or added for improved organization and accessibility. Several sections of the site have been updated or added for improved organization and accessibility.

- Policy Management was renamed Governance, which contains documents related to the governance of the OPTN, such as policies, bylaws, public comment and the evaluation plan.

- The Donation & Transplantation tab is now called Learn, with new Patient Education and Professional Education sections.

- Patient safety and organ-specific pages under Resources help professionals find important information, quickly.

A Very Different “MOVIE”

New York is a very challenged state when it comes to signing up organ donors, ranking third in the country in people waiting for organ donations and 49th in registered organ donors. So, as they say, to get different results, you have to do something different, right? The New York Organ Donor Network has taken this challenge to a new level which you can see for yourself at <http://www.LongLiveNY.org>

The recently launched animated short film “**Long Live New York**”, directed by 2014 Oscar-winner Laurent Witz, aims to change all that with a goal to ignite a movement in New York. It aims to inspire New Yorkers to step-up to help other New Yorkers, and ultimately ensure New York stays strong. It only takes 91 seconds to watch - just click on the image below . . .



In our TRIO communications we have been challenging members to do something different, something creative, to help get our message out. Kuddo's to the NYODN for this unique and well done movie that hopefully will change their donor registrations significantly.

So, what are YOU doing differently in your local world to make a difference?

TRIO's Mailing Address Has Changed.
Our new mailing address is:
13705 Currant Loop; Gainesville, VA 20155

Call for Kidney Dialysis Patient Education About Benefits of Transplantation



As also reported in both AARP and LKDN newsletters and on the TRIO web site, a new study detailed in a [recent Reuters article](#), the vast majority of kidney failure patients told researchers they saw no need for a kidney transplant because they were doing fine on dialysis. In this research report, results say these patients might not realize how much a transplant could help them.

“Nobody is doing fine on dialysis to the point where a transplant wouldn’t be better for them,” senior author Dr. Dorry Segev told Reuters Health. “Transplantation is the better form of renal replacement ...” including a doubling of life expectancy, said Segev, a transplant surgeon at the Johns Hopkins Hospital in Baltimore, Maryland.



TRIO Long Island Donor Rose Garden was host location for their chapter’s 16th annual donor recognition event, drawing over 300 attendees this September.

TRIO Awards 2014 Scholarships



Three scholarships were awarded in 2014.

Scholarships were awarded to Amanda Caruso (Rochester Institute of Technology-NY), Kayla St. Pierre (Simmons College-MA), and Marissa VanBeekum (Marquette University-WI).

Much appreciation goes to the TRIO San Francisco Bay Area Chapter and to the TRIO Philadelphia Chapter for providing \$1,000 each. The third scholarship was provided by contributions from various chapters and individuals: TRIO Manhattan Chapter, TRIO Maryland Chapter, TRIO Greater Cleveland Chapter, and individuals Elizabeth Rubin and Dennis Fogarty.

The Scholarship Committee is composed of Elizabeth Rubin, Chair; and members: Steven Binder (NEFlorida Chapter), Suzanne Himes (Greater Cleveland Chapter); Dorene Kray (Akron-Canton Chapter); Susan Pincus (Philadelphia Chapter); and Sylvia Leach (TRIO Managing Services Director).

The 2015 TRIO Scholarship Application will be posted on the TRIO website in January of 2015.

Membership – NEW or Renewal: **TRIO membership is renewable as of *January 1 each year*.**
Please support TRIO and its important work on behalf of transplant recipients, donors, candidates and their families by joining us in this important endeavor. Thank you for your support of TRIO!

Name of Member: _____

Names of other family members: _____

Address: _____

City: _____ ST: _____ ZIP: _____

Phone: _____ Fax: _____ email: _____

Member is: ___ Recipient; ___ Donor; ___ Candidate; ___ Family Member; ___ Other: _____

Recipient Profile (Optional): _____

Type of Transplant	# of Transplants	Date(s) of Transplant(s)
Name of Transplant Center(s)	City, State	Time Waited

Donor Profile (Optional): _____

Type of Donation	# of Donation(s)	Date(s) of Donation(s)
Name of Transplant Center(s)	City, State	

I would like to participate on the _____ TRIO Committee. Please contact me.
Annual Dues: Member at Large \$20.
Additional Contribution \$ _____.
TOTAL enclosed \$ _____.
Thank You for your tax-deductible donation!

**Make your check payable to TRIO and mail to:
 Transplant Recipients International Organization, Inc.
 13705 Currant Loop
 Gainesville, VA 20155**

PLEASE NOTE: If you are a member of a TRIO chapter, please pay dues to your local chapter instead of submitting this form. If you are not a member of a TRIO chapter, please consider joining a local chapter to receive the many benefits of chapter affiliation. TRIO national strongly supports local chapter membership. A list of chapters is available on our website www.trioweb.org. OR: consider starting a transplant support group or TRIO chapter in your area (contact info@trioweb.org).

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